

Case overview

- A 45 y.o. with likely familial idiopathic pulmonary fibrosis(FIPF) whose daughter was placed for adoption at birth wanted to discuss whether and how he should notify his now 23 y.o. daughter of her risk of developing FIPF

FIPF

- Progressive respiratory failure than begins between age 30-50 with progression over a period of several years
- Treatments are available but there is no data to indicate that early diagnosis or treatment improves clinical outcome
- Autosomal dominant with incomplete penetrance
 - Risk of disease influenced by smoking and exposure to pulmonary irritants

Initial Contact with Daughter

- Proband's wife (of eight years) sends a letter to 17 y.o. daughter's(J) adoptive parents, who were located with the help of the adoption agent, that states:
 - Interest in receiving information about J
 - Willingness to meet with J
 - Notification that the proband's mother had died of familial lung disease and that this might be relevant to J's health.
- J opts not to communicate with the proband or his wife
- Several letters were exchanged between proband and J's adoptive mother
- The proband and his wife do not recall whether any acknowledgement was made of the medical information conveyed in their initial letter

Subsequent Contact

- When J turned 18, the proband's wife e-mailed J indicating that J was now free to establish contact with her and her husband
- J informed her adoptive parents of the e-mail
- J parents contacted the proband and his wife and informed them that further communication was not welcome by J
- There has been no further contact between the proband and his wife and J and her adoptive parents.

Proband develops pulmonary symptoms suggestive of FIPF

- Enrolls in NIH natural history study and has just undergone lung biopsy to confirm IPF diagnosis
- Proband wants to respect J's wishes to have no direct contact with him, but he is conflicted about whether she should be informed of her risk status.
- Proband and wife are wondering what obligation do they have to inform daughter of father's diagnosis?

Questions

- Is there an obligation to inform the daughter of her risk of FIPF?
 - What are the advantages and disadvantages of disclosing the information?
 - Are there competing obligations for non-disclosure?
- Is any obligation for disclosure based on the nature of the relationships?
 - Is the obligation to the daughter or to the adoptive parents? Would this change if the daughter was only 15 years old?
 - Who has the obligation? The father or the NIH physicians?
- What is the best approach to disclosure?
 - Detailed letter?
 - Vague letter offering to talk on the phone?